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ABSTRACT

The monograph offers an overview of the history of health care for children with disabilities. Health goals for the disabled child are considered and a systems model discussed that views health care services as part of the child's total service needs. Routine and specialized health care needs of disabled children are covered, and service areas such as prevention and early detection, prenatal care, periodic screening, and primary, secondary and tertiary care are noted. The importance of linkage between health, social, educational, and vocational services is emphasized, and coordination of these comprehensive services is stressed. Planning processes for such services are noted, as is the role of specific planning bodies such as state councils for developmental disabilities, infant high-risk followup coordination committees, and professional associations. (CL)

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A Comprehensive View

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The Needs of Children with Disabilities

A Comprehensive View

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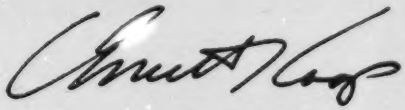
Preface

Assuring the most appropriate environment for care of the disabled child is a major concern of this administration. Whenever possible, that environment should be the community, with the child surrounded by a loving, caring family. To create this supportive climate, the family must be afforded resources from both the private and public sectors. Built on the inherent strengths of the child and family, this support system can provide the necessary environment for optimal care.

With this support system in place, we must be mindful that services for disabled youngsters are greatly enhanced when they are coordinated by the health care provider responsible for overall case management.

This series of monographs, developed by the Division of Developmental Disabilities at The University of Iowa in consultation with the Division of Maternal and Child Health of the U.S. Public Health Service, promotes the welfare of these children and their families. The Office of the Surgeon General is deeply appreciative of and responsive to the concerns and purposes represented by this series of monographs.



C. Everett Koop, M.D., Sc.D.
Surgeon General

Introduction

This monograph is part of a series which deals with comprehensive services to children with disabilities. ***The Needs of Children with Disabilities: A Comprehensive View*** offers an overview of the history of health care for children with disabilities, and presents a model which will allow the reader to view the role of health care services as part of the child's total service needs. Other monographs in the series deal with the service needs of children with particular disabling conditions.

These monographs are intended for people concerned with the planning, promotion, and delivery of services to children with disabilities and seek to promote new concepts regarding the care of children with disabilities. Over the past two decades, new coalitions of people with disabilities have become articulate advocates of their desire to lead productive participating lives with minimal disability. Advocacy efforts have led to legislation which defines and protects the civil rights of disabled persons, resulting in new and expanded health, education, and other service programs.

It is now recognized that children with disabilities have health care needs which are similar to those of so-called normal children, and it is not necessary, nor is it desirable, to separate or treat them apart from the rest of society. For a number of years the trend has been away from maintaining children with disabilities in an institutional setting and toward creating less restrictive environments for them within their own communities. Through federal legislation handicapped children have attained a right to a free appropriate public education and related services which may be required for them to benefit from special education.

The Federal Maternal & Child Health (MCH) Program has had a major role in promulgating the philosophies of prevention, early

identification, and intervention and continues to place emphasis on a developmental model of interdisciplinary comprehensive care in a family-centered context. It recognizes that disabled children with their families generally require long-term assistance across a variety of disciplines including medical, social, special education, habilitative, vocational, and community services. This total care concept is essential to the provision of comprehensive services to children with special needs.

The reader will note that the terms **disabled** and **disability** are not used interchangeably with **handicapped**, or **handicap**, as is often the case. While some would argue that the words can be used identically, the authors of this series want to make the semantic distinction for social and philosophical reasons. A **disability** is a condition which limits some physical or mental functioning of the individual. A **handicap** is an obstacle which society, or sometimes the disabled individual, places in the way of accomplishment. In the past, society has handicapped individuals with disabilities by its limited view of their potential for independence and social contribution. It is the purpose of this series to provide the health care community with a broad understanding of the services children with disabilities need to keep from becoming handicapped.

The Division of Developmental Disabilities would like to give special credit to Alfred Healy, M.D., who has served as project director for the monograph series and has focused professional expertise on this important area.

We are particularly grateful to the experts who kindly reviewed the draft documents. This monograph was reviewed by Albert Fremont, M.D., Santa Clara Valley Medical Center, San Jose; Merle McPherson, M.D., Chief, Habilitative Services Branch, Division of Maternal and Child Health; and Richard Nelson, M.D., Gillette Children's Hospital, St. Paul, with our thanks.

Special appreciation must go to Richard T. Huber, graphics supervisor, and Barbara Smith, publications supervisor, both at the Division of Developmental Disabilities, The University of Iowa, for their efforts in this project.

I. Overview

Our twins, Tom and Eric, were diagnosed as having a degenerative neuromuscular disease when they were two. Health services have always been important to us, but it is critical that we work with health professionals who can see their work in relation to the full range of services that the boys, and we as a family, need. I think there is still a gap when it comes to an overall plan for services that all concerned with care of disabled children can understand. Many parents still have to struggle with poor communication between large medical centers and local physicians, between physicians and teachers, or teachers and social service agencies. Parents and professionals should be able to share in the planning process so that sharing is not seen as a sign of anyone's incompetence but as a sign that we are all learning to do our jobs better.

We recently moved to a new town, and I actually went out and interviewed physicians to see who could best help us. I told them about the boys' disability and asked if they would be comfortable handling the kinds of things we needed, both medically and as a family. I wanted someone who wouldn't be put off by the severity of the boys' physical condition, but who would also understand the big picture. I decided on the physician who said "I don't know much about this specific disability, but I'll find out who can help us."

Tom and Eric are graduating from high school this year, against all odds, and we are making plans to send them to college. Health, educational, and social services have all helped make this possible. I want other handicapped children to have a chance to exceed our expectations too . . . it will be good for all of us.

(Parent of twins with disabilities)

Those who have a part in planning and providing comprehensive services for the disabled child have an unprecedented opportunity today for meeting the needs of children like Tom and Eric and their families. The goals of planners and providers have both humanitarian merit and great practical benefit for society. Adequate health, educational, and social services can strengthen families for the stress and added responsibility of caring for children with disabilities and make possible increased productivity and independence for the children themselves.

This monograph is about the health care service needs of disabled children. However, to deal effectively with this issue, a perspective is needed that goes beyond the specifics of health care. In a time when health care is becoming increasingly specialized and technical, developing this broader perspective, and the programs that promote it, is a great challenge. It is the purpose of this monograph to encourage the efficient coordination of the interdisciplinary services needed for the care of children with disabilities. We will first discuss health goals for the disabled child in the context of the relatively recent history of health care in this country. A systems model will allow us to view the role of health care services as part of the child's total service needs. We can then outline both the routine and specialized health care needs of disabled children and describe how services can be made accessible to them through coordination of community, regional, and state programs. Other monographs in this series will further develop this outline by addressing the service needs of children with specific disabling conditions.

THE NEED FOR A NEW VISION

Today the goals of health services for disabled children reach far beyond the simple absence of disease into services that are designed to promote the optimal functioning of the child and ultimately the quality of life available to disabled individuals. We are able to consider these types of goals only because we are in a period of time when the health status of this nation's citizens and of disabled children in particular has never been better. There have been positive changes in conventional measures of the nation's health over the past 20 years, including a decrease in infant death rates, improved availability of facilities, and increased life expectancy. However, these improvements reflect solutions to problems that were identified decades ago. Infectious disease, in-

adequate birthing facilities, and sanitation deficiencies all contributed to infant and child mortality and morbidity in this country, and health services were designed to solve these kinds of problems. The nation was ready to accept mandatory public health measures, and the results were truly impressive.

A number of factors surrounding improvements in the nation's health status over the past four or five decades are important to consider as we look at possibilities for improvement in the future. Past improvements were associated with:

1. **An increase in the availability of individual and personalized health care.** This is shown by increased per person physician visits by previously underserved populations, such as nonwhite, poor, and rural children as well as increased numbers of physicians and federal entitlement programs that provide payment for all levels of health services.
2. **Programs that required only a moderate level of personal or family commitment.** Mandatory immunization projects, food inspection, sanitation, and sewage regulations greatly contributed to improved health, with little active participation required by the beneficiaries.
3. **Programs that were directed toward mass populations, not targeted for a discrete population.** This approach was quite valid and necessary when the problems were so pervasive.
4. **Programs whose success could be measured by the lack of disease or disabling conditions.** Death rates and morbidity statistics were gross but necessary methods of determining positive change in children's health. Little concern was paid to more difficult-to-measure areas such as "quality of life" and "self-fulfillment."

Improving the health of children living in the 1980s in the United States will require a different approach. Threats to the young infant are no longer pneumonia but prematurity and respiratory distress syndrome. For the toddler, accidents have replaced scarlet fever as a potential hazard. The school-aged child no longer has to fear tuberculosis but the possibility of a learning disorder. Teenagers are not apt to contract rheumatic fever but may be threatened by suostance abuse, motor vehicle accidents, and possible suicide. Today's health problems reflect a concern for morbidity instead of mortality, quality rather than quantity of life. New planning measures to improve health care must involve the following:

1. **An active personal participation in solutions.** There must be increased personal participation in solutions to health problems. In the case of the young disabled child, this will require family participation. Because of the pervasive nature of so many disabling conditions, plans which include treatment only by a professional without parental understanding and involvement will be less than effective. Programs must be developed that help disabled individuals control decisions that influence their lives.
2. **The focusing of scarce planning and funding resources on discrete populations with particular problems, not on programs for the nation as a whole.** The focus of resources on discrete populations in the case of disabled children will mean looking at functional limitations rather than medical diagnoses and allocating resources accordingly. Not all children with cerebral palsy need orthopedic surgery; not all children with spina bifida need special education. Targeting sophisticated technology toward those who really need it will bring about improvements in health and also make more efficient use of resources.
3. **A close association between the child and health care practitioner in a community-based nonhospital setting.** Movement away from institutional care into the mainstream of community life brought about great improvement in educational, vocational, and social adjustment for disabled individuals. Providing the bulk of health care in nonhospital settings with a focus on "generic" programs that support specialized clinics is both cost efficient and normalizing for the child and family.
4. **More subtle ways of measuring the success of health care programs.** The nation has demonstrated a commitment to "quality of life" as a viable goal for the disabled individual through legislation that offers access to education, employment, and other aspects of a full life-style. The success of health care programs will not be judged by indices of life expectancy and mere freedom from disease, but by how they contribute to the "quality of life" goal.

4

Health programs must consider the disabled individual's functional limitations and address specific needs resulting from them. As D. L. Henderson states, "Solutions today must transcend the conventional boundaries of curative medicine . . . and identify objectives that will require an active partnership with educators,

environmentalists, behavioral scientists and politicians alike in the interest of healthier children" (Henderson, 1981).

HEALTH CARE AND THE CHILD'S LEVEL OF FUNCTIONING

Health problems can influence development on either an acute or a chronic basis. If short-term, there will be minimal effect on the child. If the health problem persists the developmental progress of the child can be delayed or altered to a degree that it can be considered a disabling condition.

The health care needs of the disabled child need to be considered in the context of the health care needs of all children. The following model is based on a broad view of health which considers the functioning of the child in a supportive, nurturing, family-oriented environment. Such a model implies an interaction between the child and the environment not just for physiological survival, but for optimal child development and later adult functioning. The child's relative ability to function, not the diagnostic label of any specific disability, tells us whether and to what extent a child is disabled and what services he or she needs. There are three main systems we use to judge the status of a child's functioning. These three systems are:

5

SENSORY INPUT SYSTEM

Information is conveyed from the external world into the central nervous system via the sensory organs of audition (hearing), vision, smell, touch, proprioception, and kinesthesia.

CENTRAL PROCESSING SYSTEM

Data gathered through the sensory input system are correlated with memory and processed via intellectual and cognitive channels into discrete ideas and concepts.

MOTOR OUTPUT SYSTEM

The ideas and concepts generated from intellectual processing are communicated back into the world via motor (muscular) activities. Speaking, writing, working, walking, and playing are expressions of thought—which require muscular activity.

Through the functioning of these three systems shown in Figure 1, the child communicates and is judged by siblings, parents, teachers, and friends, receiving various kinds of feedback in return. The child receives feedback via the sensory input systems, allowing the modification and refinement of future motor activities, which are signals of the child's learning.

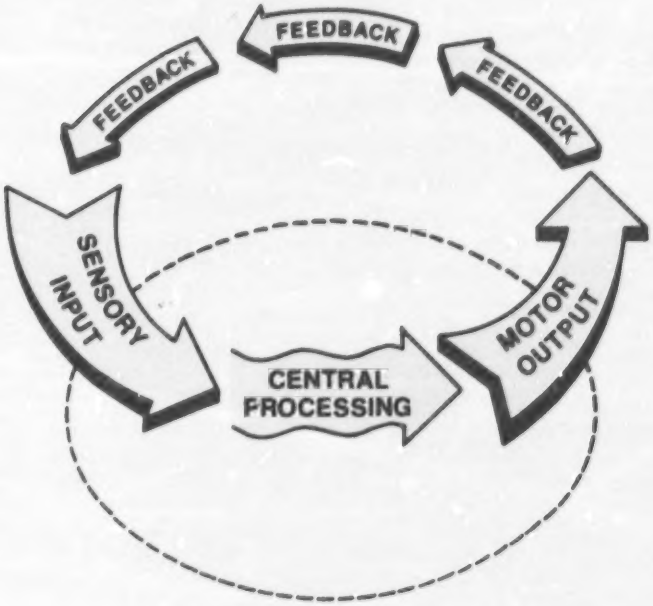


Figure 1: Sensory input, central processing and motor output systems.

The child's ability to control or use these systems to interact or communicate requires optimal functioning of two other systems.

PHYSIOLOGICAL HEALTH

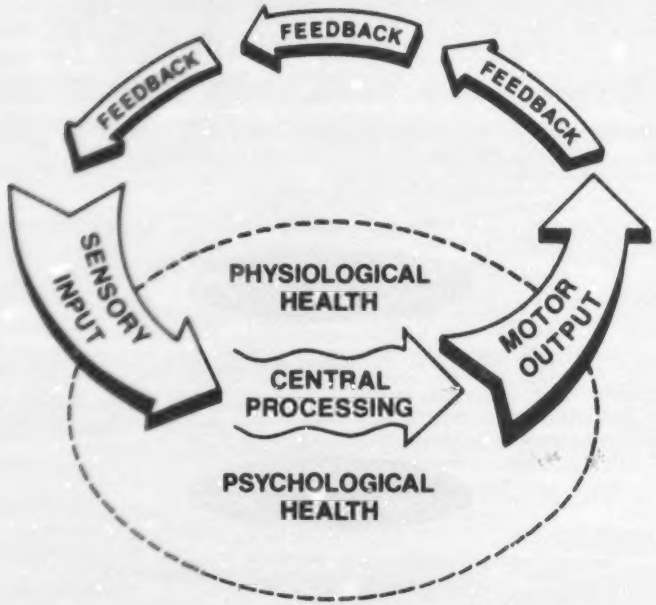
In order for sensory input, central processing, and motor output to proceed optimally, a constant source of energy must be available, provided by intact respiratory, digestive, cardiovascular, endocrine and elimination capacity.

PSYCHOLOGICAL HEALTH

The state of emotional or mental health contributes to the child's functioning, affecting perceptions (input), thinking (central processing), and desire to communicate (output). A positive feeling about oneself is often seen as an essential component of good mental health and critical to optimal development.

As shown in Figure 2, the child is in a constant state of interaction with the environment. The child is dependent on a stimulating environment, but must have functioning components of the sensory input, central processing, and motor output systems in order to learn from it. Health, both physiological and psychological, is a necessary part of optimal interaction with the environment and all attempts to influence the child's cognitive and personal growth are influenced by it. Each component contributes to the overall functioning of the child—and understanding that level of functioning becomes the starting point for guiding developmental progress.

Data for all learning and subsequent behavior enters through the sensory input system. However, the motor output system offers the evidence we use to judge the status of the other systems. An 18-month-old child who cannot stack three blocks as part of a screening test is not exhibiting age-appropriate behavior. The reason for this inability can be discovered only after a complete assessment of the sensory input system (e.g., vision and hearing), central processing system (e.g., cognitive, auditory processing, and memory), the motor system (e.g., strength, tone, coordination), the environment in which the child receives feedback (e.g.,



8

Figure 2: Physiological and psychological health are necessary to support the ongoing functions of sensory input, central processing and motor output.

presence of nurturing parents and supportive siblings and peers), the presence of optimal physiological health (e.g., intact cardiovascular and neurologic systems), and the status of psychological health (e.g., rational and oriented thought, appropriate affect and mood). Only after such a complete assessment could a definite conclusion be reached as to why the child could not stack the blocks. At the present time, all developmental screening projects depend upon the observation of motor behavior to detect problems of input or central processing. (The use of evoked responses is rapidly expanding but is not yet clinically available for large populations.)

The use of this input-output model to assess the status and needs of children permits physicians, nurses, therapists, and

other health care professionals to integrate traditional developmental and health care information into a picture of the "whole child." Understanding that a congenital heart defect such as a ventriculoseptal defect (VSD) affects not just physical health but other systems allows a physician to determine whether the health disorder should be classified as a disabling condition. Characteristics of disabling conditions are outlined below.

DISABLING CONDITIONS:

require a significant deviation from care provided to most children by the primary care provider prior to formal school years and appear to be permanent;

and/or

require a significant change in the program (setting or service) in the formal school program over time and appear to be permanent;

and/or

require management techniques or settings that significantly disrupt a child's long-term efforts to develop self-worth, self-confidence, or effective peer or sibling relationships;

and/or

result in enough variation from usual child functioning or appearance that undue attention is focused on the condition and optimal learning or other social experience cannot be obtained.

This composite approach not only permits accurate interpretations of the individual child's strengths and weaknesses, but also can be used to analyze large group data to determine trends in the health of child populations.

II. Service Needs

Disabled children are a subgroup whose health needs have often been misunderstood and underserved. A service delivery system that considers the diversity of needs contained in the subgroup will do much to promote the quality of life and productivity of these children.

To assure the proper delivery of the comprehensive services needed by disabled children, **a health care plan must consider the disabled child not as a sick child but as a well child with a disability.** There is still a tendency, even among some health professionals, to view disabled children as unwell and to see their health care being performed in a segregated environment. A mentally retarded child, or a blind child, as examples, may not have any unusual medical problems. In other cases, the disabling condition itself may be medically related, such as in the case of the asthmatic child or the child with spina bifida. The children are best and most economically cared for in the mainstream of the health care system, where they have access to the full range of primary, secondary, and tertiary services . . . not in a system set aside for the exclusive use of the disabled.

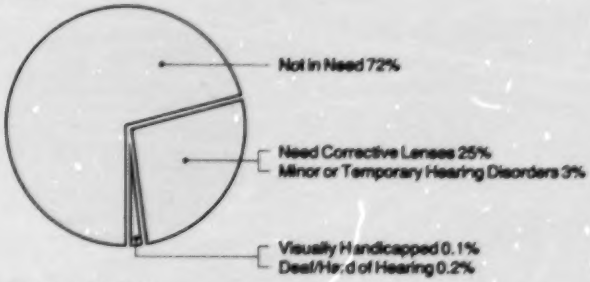
11

THE POPULATION TO BE SERVED

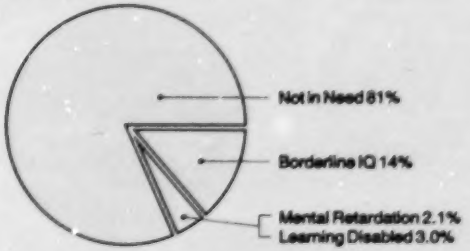
Impairments of functioning serious enough to be considered disabling can originate in any one or several of the five systems illustrated in Figure 1. The comprehensive services required by children classified as disabled will vary with the system or systems affected and the relative severity of the impairment. Planning a health care delivery system to meet the needs of this group of children must be done with an understanding that these needs are part of a continuum of health care shared largely with all children.

Of the approximately 225 million people in the United States today, 80 million are infants, children, and young adults under the age of 21 years. Based on information available from a number of sources, Figures 3a and 3b show the status of these individuals relative to the systems shown in Figure 1.

SENSORY INPUT


Not in Need 72%
Need Corrective Lenses 25%
Minor or Temporary Hearing Disorders 3%
Visually Handicapped 0.1%
Deaf/Hard of Hearing 0.2%

CENTRAL PROCESSING



MOTOR OUTPUT

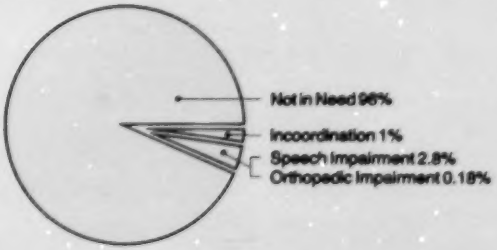
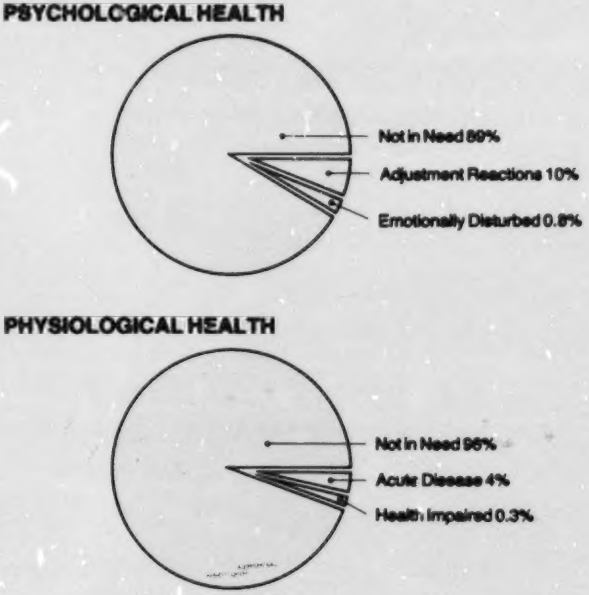


Figure 3a: Health status of U.S. children and young adults, 3-21 years of age, relative to sensory input, central processing and motor output.



13

Figure 3b: Health status of U.S. children and young adults, 3-21 years of age, relative to physiological and psychological health.

At birth, 1-2 percent of all infants have discernible disabling conditions. By age five years, approximately 8.5 percent of all children in the United States have disabling conditions as determined by Public Law 94-142 and Public Law 91-313. Other estimates project that between 11 and 12 percent are disabled. Almost all the disabilities identified at birth are in the sensory input, motor output, or physical health systems. Few central processing problems are identified at birth except in those syndromes which are known to be associated with them, such as Down syndrome and Trisomy 18. Only after 12 to 18 months of age can the central processing difficulties of moderate degrees of retardation and, after three to four years, learning disabilities, be diagnosed. The greatest number of children with disabilities are served during the elementary school-age years when the vast majority of the disabl-

ing conditions served through the educational system involve the central processing system, and their remediation is basically through educational strategies.

The diversity of estimates and difficulty in interpreting them is problematical. One effort of people involved in service to the disabled on local, state, or national levels should be to develop a uniform concept of the size of the population being served and the specific disabling conditions involved. A truly comprehensive view of the needs depends on this effort.

SERVICE AREAS

The disabled child's health service needs can be the same as the needs of so-called "normal" children or can involve the most extreme forms of medical intervention. Health impairments are frequently part of or contribute to developmental disorders. For example, the primary disability of children with Down syndrome is in central processing, with mental retardation being a feature. However, hearing deficits, cardiac lesions, motor deficits, and frequent upper respiratory problems are also often associated with this disability. The full role of the health care professional in the management of the Down syndrome child cannot be defined without a complete assessment of the child. The following service areas, however, will need to be addressed for most disabling conditions.

Prevention and Early Detection

Improvement in health indicators relating to disabled children will not be achieved without adequate prevention and early detection services. Education for prenatal care through participation in Maternal and Infant (M & I) projects, prenatal nutrition programs, high-risk pregnancy monitoring, and genetic counseling may all be considered prevention services, along with services such as screening for metabolic diseases (e.g., PKU) in the newborn period. An infant born at 32 weeks gestation who requires ventilatory assistance may be at risk for developing spastic diplegia (cerebral palsy), but still has an excellent chance of avoiding central processing difficulties. Without periodic screening for developmental and health disorders, this at-risk child will not have early attention paid either to the developing spasticity of the lower extremities or to the possibility of pulmonary complications secondary to bronchopulmonary dysplasia. Neither the parents nor others concerned with the child's progress will be able to deal

optimally with the child's problems.

Other at-risk groups needing systematic health assessment include infants born to mothers with health disorders such as diabetes or severe toxemia, infants experiencing hypoxic or ischemic insults, very low birth weight infants, infants exposed to high concentrations or pressures of oxygen or who receive ototoxic drugs, and those whose parents are not emotionally or socially able to nurture a child. These are only examples of the many conditions with secondary complications that can be prevented or reduced through early detection and remediation. The availability of these services will do much to alter the incidence and severity of many disabling conditions.

Methods for early detection of disabling conditions include prenatal and newborn screening, infant high-risk follow-up projects, Early Periodic Screening, Diagnosis and Treatment services (EPSDT), clinic or private health care provider screening, educationally oriented preschool screening projects, and the use of academically oriented screening tools in the early elementary school years. Obviously, those children who have the onset of medically related disease during childhood, or those who experience traumatic injury, require immediate identification and provision of care.

Prenatal Care

Careful prenatal care, coupled with amniocentesis, ultrasound, and other diagnostic techniques can identify infants with neural tube defects (myelodysplasia), certain chromosomal abnormalities (Down syndrome), major anatomic deficits (microcephaly), some metabolic conditions (kidney agenesis), and possible effects of maternal infection (toxoplasmosis). Certain prenatal information can identify in advance mothers whose babies may be at risk for problems such as prematurity and respiratory distress, in order that proper care can be provided at delivery.

Newborn Screening

Approximately 1-2 percent of all babies have discernible disabilities at birth. Some disabilities can be seen (congenital amputation of an extremity), some require physical examination for detection (congenital heart disorder) while others require laboratory confirmation of problems such as maternal infection (toxoplasmosis). All infants require **screening** for the detection of specific

genetic conditions that can cause disorders if not detected early (e.g., PKU, hypothyroidism).

Infant High-risk Follow-up Projects

Some infants (estimated 5 to 7 percent) experience clinical conditions or treatment situations (neonatal sepsis, resuscitative efforts) that do not produce clinically discernible conditions during the neonatal period, but place the babies at high risk for later manifesting signs of mental retardation, cerebral palsy, or learning disabilities. These infants need regular, periodic evaluation of their development through standardized screening instruments combined with neurodevelopmental examinations to detect early deviation from developmental and growth norms.

Periodic Screening in Private Practice and Clinic Settings

Periodic screening for developmental disorders and disease during child health supervision activities are needed both in private physicians' offices and clinic settings. The physician or group providing ongoing health care should have written communications from nursery staff regarding the status of newborns. Periodic assessments using procedures recommended in the American Academy of Pediatrics' *Standards of Child Health Care* (1977) should follow. Selected groups of children are eligible for funding for such services under the EPSDT program.

16

Early Education Oriented Assessment

As a child progresses from less than 24 months of age through 36 months of age, a reorientation of the "disability detection" system is required. From 36 months on, newly identified conditions are most apt to be mild mental retardation, learning disabilities, language dysfunction, and emotional disorders—problems often not detected until a child is involved in educational programs. (Recent efforts of both preservice and in-service education of physicians and other health professionals are improving the ability to identify children under three years of age who show early signs of central processing difficulties.) The function of identifying central processing or social problems complements the earlier functions of the health care portion of the detection system, when the majority of problems identified were related to sensory input and motor output. Unnecessary duplication of efforts can be avoided with adequate communication between the personnel involved in

the early sensory and motor screening and those involved in later cognitive processing screening. Cooperative planning allows the majority of all disabling conditions to be known and evaluated either prior to or during the child's first two years of school (kindergarten and first or second grades) before secondary complications can interfere with the primary habilitative efforts.

Identification Systems for Elementary School-aged Children

After the age of three to four years, medically based identification of disabilities decreases, and children are more likely to be seen by physicians for illness than for developmental assessment. Diabetes, asthma, collagenvascular and neoplastic diseases, or emotional or psychiatric disease, are conditions that often appear first during the school years. Teachers, school nurses, counselors, and administrators need to be sensitive to presenting symptoms and assist the family in communicating with private or public health practitioners so that these health problems are treated before they become disabilities.

Secondary School Identification Systems

Alcohol and substance abuse, teenage pregnancy, obesity, emotional disorders, motor vehicle accidents, and violence including homicide and suicide attempts are problems that primarily affect junior and senior high school students. These problems can lead to temporary or permanent disabling conditions. Much responsibility, again, must fall on school personnel to see that students with problems are assisted in reaching the necessary health professionals.

PRIMARY, SECONDARY, AND TERTIARY CARE

We have emphasized that health care for disabled children is best delivered through the main system of health care services. For children without extraordinary health care needs it is both most normalizing and most economical to have them cared for by primary care physicians as much as possible. A significant portion of all children with disabilities can be adequately cared for through such a system.

For the handicapped child with more complicated health needs, which often are both chronic and multidisciplinary, access to the full range of care available through secondary- and tertiary-level centers is critical, with specialized care coordinated with local

care. An estimated 15 percent of disabled children require this level of care. Availability of and access to such care is a major concern as modifications of the current health care system are planned and implemented.

A 14-year-old girl with meningomyelocele repaired at birth may have flaccid paraplegia, a sensory deficit below the lesion, and a neurogenic bowel and bladder. She needs access to a variety of health professionals—including physicians, therapists, nurses, nutritionists, and social workers on a regular basis. She may also need periodic attention to upper respiratory infections, urinary tract infections, and possibly intestinal problems. Each disorder may require a different level of care ranging from primary care of respiratory and urinary tract infections to complicated orthopedic procedures in tertiary-level care centers. Each level of care, however, must be coordinated through one member of the health care team.

The primary care physician should know where services for disabled patients can be obtained, from secondary specialists in neighboring communities to distant tertiary medical centers, and should share information and decision making regarding the use of such services with the parents and child. Whether the service provider is classified as primary, secondary, or tertiary is not of major concern. The question should be "Where can the child receive the best health care by qualified personnel in a way that considers not just the excellence of that service, but the emotional, educational, and financial concerns of the patient and family as well?" Obviously, not all problems can be cared for by primary care physicians, nor can all health needs be met in a tertiary setting. The need for sophisticated specialists and up-to-date technology must be balanced with the need for closeness to community support systems. When secondary or tertiary care is required, the health service plan should help the family remain intact by releasing the child to community health care personnel as soon as practical, or at least by having accommodations available that support family unity.

The roles of primary, secondary, and tertiary health care services will vary greatly with the individual child and with the medical facilities available in the home community. For general purposes, we will outline here the function and staffing of primary, secondary, and tertiary health services as they relate to children with disabilities.

PRIMARY HEALTH CARE FOR DISABLED INFANTS, CHILDREN AND YOUNG ADULTS

Provide acute care of nonrecurring conditions (e.g., lacerations) or recurring conditions (e.g., URIs) not related to the primary disability.

Provide chronic care of conditions not related to the disability (e.g., acne or minor allergic condition)

Provide initial evaluation and referral for children with suspected disabilities (e.g., motor dysfunction in a nine-month-old infant)

Provide chronic care of certain conditions related to the disability (e.g., urinary tract infection in a child with meningomyelocele)

Implement treatment or evaluation procedures suggested by secondary or tertiary personnel (e.g., change in medication for child with complicated seizure disorder)

Share responsibility of care with a tertiary facility for long-term physiological health disorders (e.g., leukemia)

19

Initiate care for a complication resulting from a disability (e.g., setting a fracture in a child with osteogenesis imperfecta)

Coordinate and communicate health care plans of individual children with the school system (e.g., child with attention deficit disorder)

Provide ongoing support and counseling to parents of disabled children

In addition to physicians, primary health care for disabled children involves nurses, physical and occupational therapists, speech clinicians, audiologists, social workers, dentists, psychologists, and nutritionists. Currently there are a variety of clinical practice models that allow these professionals to influence the developmental process of disabled children while working in an interdisciplinary fashion.

The same professionals provide service both at the primary and secondary level of care. However, at the secondary level, in addition to providing direct service, most therapists, nurses, and other clinicians coordinate and plan services for the disabled population as a whole.

SECONDARY HEALTH CARE FOR DISABLED INFANTS, CHILDREN AND YOUNG ADULTS

Provide evaluations of children referred from primary care physicians (e.g., infant with suspected cerebral palsy)

Provide care for children with moderately complicated disorders (e.g., learning disability with behavioral overtones)

Provide care for children with secondary complications of the primary disability (e.g., obesity in a child with muscular dystrophy)

Coordinate care between individual professionals and agencies (e.g., child with myelodysplasia)

Provide training to community professionals regarding total care of disabled children (e.g., discuss health care needs of disabled children with local teachers' group or local public health nurse)

Provide ongoing support, education, and counseling for parents of disabled children

At the tertiary care level essentially all health disciplines are required to provide comprehensive care to disabled children. The majority of professionals provide consultation and recommendations for care as well as direct patient services. The strength of university- or medical-center-based programs lies in the professional

competence and experience of their respective staffs, and their ability to interface effectively with the health care system in the community.

TERTIARY HEALTH CARE FOR DISABLED INFANTS, CHILDREN AND YOUNG ADULTS

Provide evaluation and diagnostic services for complicated disorders requiring sophisticated techniques and procedures (e.g., child with Maple Syrup Urine Disease)

Coordinate and provide medical and surgical care for complicated and multiple disorders (e.g., child with myelodysplasia)

Provide "second opinions" in management discussions between agencies and/or parents (e.g., regarding the need for a particular service or piece of equipment)

Initiate innovative care programs for particular disorders (e.g., beginning new medication for a child with previously uncontrollable seizure disorder)

Provide preservice and in-service didactic and clinical training for all professionals preparing to work with the disabled population (e.g., university course regarding value of interdisciplinary method)

Participate in clinical research projects that enhance the delivery of health services to disabled children (e.g., study on communication skills required by physicians to best deliver distressful information to parents)

COMMUNITY SUPPORT SERVICES

The resources to identify and treat health problems of the disabled child are limited. To be effective they must be allocated according to well-conceived plans that emphasize coordination of community resources so that services are available to children in need, but also so that services are not duplicated and/or do not lead to conflicting management plans. A three-year-old identified as developmentally delayed during a preschool developmental screening exam may have the need for a variety of diagnostic and

treatment services. Features of a coordinated community plan are outlined below.

FEATURES OF COMMUNITY PLAN FOR EVALUATION AND CARE

Assurance that all appropriate newborn metabolic screening exams have been accomplished and that all appropriate medical and social risk factors have been identified and recorded

Evaluation of vision and hearing, with recommendations for further evaluation or care if needed

Evaluation of cognitive and intellectual functions, including adaptive and language abilities, by licensed or certified personnel, with recommendations for further evaluation, if necessary

Evaluation of motoric abilities, including speech skills, with recommendations for further evaluation, if necessary

Evaluation of medical and dental health, with emphasis on detection of all medically or surgically remediable disorders, with recommendations for further evaluations or treatment, if necessary

Evaluation of mental and emotional status, with recommendations for further evaluation or care, if necessary

Evaluation of the family, school, and other social influences on the child's functioning

Generation of a coordinated plan that integrates all required further evaluation and treatment procedures to be provided through or by medical, dental, social, educational or private resources, with primary concern for the family's desires and with their assistance and approval

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LINKAGE BETWEEN HEALTH, SOCIAL, EDUCATIONAL AND VOCATIONAL SERVICES

A child's sensory input, central processing, and motor output systems all depend on sound physiological and emotional health to operate efficiently. Any efforts to remediate disabling conditions will be affected by the general health status of the child. Health care devoted to elimination of respiratory, cardiovascular, or bowel and bladder conditions, seizure disorders, orthopedic impairments or chronic dermatologic disorders will give the child a better chance of profiting from educational interventions. Similarly, specific therapy directed toward helping a child cope more effectively with stress or emotional or behavioral disorders will also increase the success of educational and social interventions. Therefore, all human service agencies should be aware that children need to be in an optimal state of physical and emotional health if learning and social goals are to be realized. Health care provided without this understanding and the service network to back it up will be less than effective.

TRAINING AND RESEARCH NEEDS

Both laboratory and clinical research, as well as professional training, should be part of a comprehensive plan of services for disabled children. The research needs in prevention, diagnosis, and treatment vary with the specific condition and the health delivery system used.

While increased research is needed to bring improved technology to bear on specific problems of the disabled, a more urgent need is to ensure that health service professionals on the primary, secondary, and tertiary level have the training to use existing technology effectively as part of a comprehensive, interdisciplinary service system. Viewing a disability as a sign of poor health interferes with the diagnosis and treatment of the disabled child's health problems. Training programs must address this still common misconception. Most health professionals, especially physicians, are trained in a "curing" model, not in the "coping" model which is more appropriate for approaching the problems of the disabled child. Working with children whose basic problems cannot be dramatically altered by modern medicine may be an unsettling experience for some. Improved professional training should address the physician's need to understand and feel comfortable with disabled children, as well as the need for medical in-

formation on specific disabling conditions.

Some universities are approaching part of these training needs by offering courses in interdisciplinary programming for disabled individuals. These courses bring students from many disciplines such as medicine, special education, speech pathology, and recreation, physical and occupational therapy together at the preservice level. They learn about the history of providing services to the disabled. They become familiar with each other's service roles and develop a sensitivity to both service needs and providers that will aid in effective coordination of care. These training programs are often found in University Affiliated Facilities (UAF's).

III. Coordination of Services

The multifaceted and chronic nature of the health problems of disabled children today call for a health care delivery system that does the following:

- Considers optimal health care for disabled children as part of optimal health care for all children
- Uses an interdisciplinary process with a stable, coordinated, and continuous management system of primary, secondary, and tertiary level health care
- Focuses on supporting the family's extra social, emotional, and financial concerns relating to the disabling condition
- Has an assessment and management plan that takes into account the family, school, and other social environments in which the child functions
- Has incentives for preventive care, comprehensive community care, and care focused on outpatient services.

The basic service needs that should be made accessible by this system have already been outlined. In this section we will consider a plan that will insure that these services are available. The coordination essential to comprehensive services for disabled children with complex needs is really a process by which the various service areas communicate with each other for the benefit of the child and the efficiency of the system.

The extensive Rand Corporation Report of 1979, ***Handicapped Children: Strategies for Improving Services***, emphasized that current inadequacies of services to handicapped children in this

country are not primarily a result of lack of good programs or a lack of caring on the part of legislators, service providers or parents. Nor are the gaps primarily caused by funding problems, although funding is a continuing concern. The main problem the Rand report found was that IN ALL AREAS OF COMPREHENSIVE SERVICES THE OVERALL QUESTION OF WHO IS DOING WHAT FOR WHOM IS NOT ALWAYS UNDERSTOOD BY THE VARIOUS PARTIES INVOLVED (Brewer and Kakalik, 1979).

As one segment of comprehensive services for handicapped children, the health care sector has more problems with this basic question than either social services or educational services. Earlier in this discussion, we reviewed some of the major types of programs involved in the early identification of disabled children, a first step in delivery of any kind of service. But what happens to the child in need of health services once identified? Both social and educational services have established administrative channels for providing services to the child in need. Although there are gaps and inequities in services, social services and educational systems do have a plan for getting the child experiencing educationally related disabilities into a system where services are available. There are also established procedures to pay for these services.

For the health sector the procedure is not as clear. Certain kinds of health services are provided through the educational sector, while others are available only at tertiary centers. Much can be provided by local pediatricians and other primary care physicians. Funding may come from the families themselves, from Medicaid (Title XIX), SSI, private insurance, or from private agencies. The family attempting to find out what is available for a disabled child and how services can best be provided and paid for is sometimes faced with excellent services and funding possibilities but no clear-cut procedures for securing them. The health care plan for a disabled child is often put together through the struggles of determined parents—parents who more than most have a need for a responsive health care system. Primary care physicians trying to provide health services for this family are faced with difficult questions about what their role should be.

How should a plan of coordinated services be structured? Stanley Graven, one of the pioneers of the perinatal care delivery system, devised a series of recommendations regarding community planning and coordination that are applicable to the disabled

population. They include these points:

- People and institutions must be cultivated and encouraged to do things, not ordered or directed.
- Areas or regions should be of manageable size and fall into logical areas which provide some common basis for addressing problems and developing solutions.
- Constituencies and coalitions must be developed in each area, and problems must be divided into manageable-sized component parts.
- Efforts should be focused on achieving small but long-term or permanent gains.
- Sequence and timing are usually crucial for success—some issues and problems need to be left alone for periods of time while others need to be addressed promptly while the opportunity exists.
- Finding and involving the right people is essential.
- Professionals and patients do care—no one wants adverse outcomes.
- Health care is closely tied to family, culture, and religion and should be delivered as close to home and support systems as is possible.

From these principles, general characteristics of a delivery system can be stated.

- The system evolves from community individuals using plans and strategies that enhance coordination and cooperation.
- The area selected as a "community" base must have practical, usually already functioning boundaries. The boundary may be educationally, socially, or medically determined, but there must be final consensus as to its specificity for the particular system planned.
- No plan for coordinated services will succeed if all necessary partners are not included: providers of all levels and types of health care, patients, parents, and representatives of funding resources through private and entitlement programs.
- Community-based programs that demonstrate coordinated, efficient care are based on negotiated relationships that allow each individual professional and involved agency their right to first demonstrate their concern and willingness to cooperate (Graven, 1981).

Who can put this plan together, and how is it done? It is clear that a rigid, detailed service plan for disabled children, handed down to local areas from the federal or state governments, is not appropriate. The plan should allow communities considerable variation to meet their particular needs. Pronouncements from above will not accomplish the overall goal of providing services as close to the child's home as possible, nor the ideal of providing most health care for the disabled child by local personnel. The planning must start at the community level following general guidelines determined by state agencies.

But what kind of planning are we talking about? The term "planning" here does not mean the dictation of specific services, but a process of communication for the various groups concerned with disabled children. Although it would depend on the community, a planning body would almost always include social service, educational and health service representatives as well as parents and religious leaders and representatives of charitable civic organizations. The term "community" will need to be defined differently in different areas. In some rural states, a "community" might consist of several counties in the same region of a state. In other states, a community might represent only one city or heavily populated township. The representative body meets in the beginning not to identify what services need to be available, but first to share information. What are these various representatives doing to serve disabled children? What services actually exist in the community? How many disabled children are there? An example of the importance of the communication process lies in the various early identification and screening programs. The health care sector may have an infant high-risk follow-up program, which identifies children at risk for developmental problems from birth. Social services may implement EPSDT programs while "Child Find," an educationally organized preschool screening program, reviews the same children for similar disorders. These are all excellent community-based programs, but often the programs do not communicate or plan with one another. It is this lack of communication which can lead to both duplication of services and gaps in services where children in need are missed altogether (Hulme and MacQueen, 1981).

In areas where these kinds of coordinating bodies are being created, participating health care professionals often have an eye-opening experience. As individual cases are brought forth, it

may be that social services has served a family for many years because of the need for family assistance. The education agency has also had data on the family through the individual educational plans and various school screening projects. It is often the local physician who has not had a consistent pattern of dealing with the child and family, because the delivery of health services has been so divided, and because the treatment and results from other sources have gone unshared.

Even though this forum, or communication and planning body, will assess the overall status of services to the disabled, it is not a body that will deal specifically with all disabled children. Children identified in "Child Find" needing speech therapy, for example, or identified as having a learning disability, will receive services through the school system and their local physician. If no other complications are involved the children are not really in need of integrated services. On the other hand, a child severely disabled by spina bifida, from a family with social and financial problems, will need the kind of integrative planning that a community body can provide. Can the local health services handle the child's problems? How much care will the child need at a tertiary center? Can social services secure rehabilitative help for an alcoholic parent? Can the local civic organization finance equipment for the child? How will health care professionals in the private sector be paid for their services? In short, who is going to take what share of the responsibility for the many services needed by this child?

Children who need this kind of highly structured integrated planning form a small portion of the disabled population as a whole. It is suggested that 85 percent of disabled children can secure adequate care through management by single agencies or professionals working informally with other providers, such as in a case where a pediatrician contacts a child's teacher. Approximately 15 percent need the kind of integrated planning that this community body would handle. For the health care needs of this 15 percent, the commitment of local health services should be a strong one. It is possible that only as many as a quarter of the children needing this integrated care require, in addition, medical care at a tertiary center.

There is increasing evidence that all contemporary health service delivery plans will reflect concern for cost containment and service efficiency. Similar concerns are being expressed for educational and social service programs for disabled children and

young adults. For children with disabilities, it seems logical to plan, deliver, and coordinate health services with those agencies that share common goals and contemporary constraints. The effect of such coordination can be greatly magnified when the planning occurs at a local level, as close to the delivery source as possible.

Those legislative programs that retained a federal presence to serve as national training, data gathering, and planning and coordinating resources effectively use ad hoc and other technical advisory committees to assist in planning national projects. By sharing results from other effective statewide projects they will continue to offer advice and recommendations.

Effective planning bodies dealing with programs for disabled children do exist in many states. Examples include:

- State councils for developmental disabilities
- State Maternal and Child Health advisory committees
- Health service agency planning bodies
- Crippled Children's Services planning committees
- State advisory panels for the Education for All Handicapped Children Act
- Infant High-risk Follow-up coordination committees
- Professional associations.

Five specific planning bodies, bringing statewide attention to the needs of disabled children, would influence approximately 100 percent of children currently labeled as disabled in any one state. They are:

- The state advisory panel for the Education for All Handicapped Children Act (PL 94-142)
- The state council on developmental disabilities (PL 95-602)
- The advisory body planning and allocating Medicaid funds (Title XIX)
- The advisory body planning and allocating Title XX services
- The advisory body for Maternal and Child Health Block Grants (including Crippled Children's Services and SSI).

Each of these committees or councils has statutory ability to influence the rules and regulations that implement the law, or to recommend the allocation of funds directed toward the disabled. Each of these groups is operational in most states. The need is for them to communicate common concerns and integrate their planning processes at a state level—and to demonstrate by example

to local communities the value and efficiency of cooperative planning. The appointment of health care personnel to these administrative committees is critical if an interdisciplinary forum is to emerge.

IV. Summary

The statement "change is the only real constant" is extremely applicable to the needs of children with disabilities. In addition to traditional disabling conditions, we are currently experiencing conditions and diseases unheard of only a few decades ago. Children with the sequelae of Reye's syndrome, bronchopulmonary dysplasia, those with methylmalonic acidemia, or hyperalanemic phenylketonuria are manifesting either new conditions or subtle variations on old disorders that require new approaches to rehabilitative care.

The health care system must respond to both the "traditional" and newer disorders through a system of care that is based on a process—a process that reviews all the "systems" used by children to cope with and learn from their environment. Only when each professional has an appreciation of how an individual child's abilities interrelate in the child's attempt to override the effects of a disability can effective screening, evaluation, diagnostic and treatment plans be structured. This individualized planning requires a solid foundation of coordinated cooperation at all levels—community, state, and federal—as the tenets of the system evolve.

Coordination begins with knowledge—knowledge of shared concerns and functions and data regarding the populations to be served. It is accomplished through communication and perseverance. The disabled infants, children, and young adults of this country need and deserve this coordination.

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